

**MĀORI AND PALLIATIVE CARE:**  
Literature review report for  
Te Ohu Rata Aotearoa

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## Forward

This report was written by Kat Mason with support from Dr Tess Moeke-Maxwell (and the Te Ārai Palliative Care and End of Life Research Group, School of Nursing, University of Auckland) on behalf of Te Ohu Rata Aotearoa. The purpose of the report is to inform the development of an evidence-based framework to support culturally appropriate palliative care provision for Māori, through identifying:

1. National evidence and research:
  - a. Exploring Māori experiences of palliative care
  - b. Identifying outcomes for patients and their whanau/families
  - c. Māori palliative care services and models of care
  - d. Cultural competency/safety training
2. International evidence and research:
  - a. Exploring Indigenous experience of palliative care
  - b. Identifying outcomes for patients and their families
  - c. Indigenous palliative care services and models of care
  - d. Cultural competency/safety training

# Introduction

Within the context of Māori end-of-life journeys, the palliative care discourse is relatively new. Māori practices surrounding illness, dying and death are guided by *tikanga Māori* (a set of protocols) based on principles and values informed by *mātauranga Māori* (Māori knowledge base) (Mead, 2003). The Tohunga Suppression Act 1907 and other colonising policies interfered with traditional Māori structures and suppressed *tikanga Māori* (Mead, 2003). It forced Māori healers underground, disrupting, but not eliminating, the transfer of their philosophies and systems to future generations (Durie, 1998).

Palliative care has been defined by the World Health Organisation (2002) as “... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (p. 84). This definition resonates well with Māori concepts of health such as *Whare Tapa Whā*<sup>1</sup>.

The strategic context of palliative care service provision and funding within New Zealand is guided by The New Zealand Palliative Care Strategy (Ministry of Health, 2001) and vision statement that “[all] people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way” (p 7). A critical point we wish to convey in this document is that the provision of palliative care services goes beyond that of formal palliative care providers (for example specialist palliative care services). It includes all health professionals and providers who come into contact with patients with palliative care needs and their whānau/family, for example hospital and primary care services, disability support services, Primary Health Organisations, Māori health providers, rest homes

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<sup>1</sup> *Whare Tapa Whā* is a Māori model of health that is founded on four key concepts of *taha wairua* (the spiritual side), *taha hinengaro* (thoughts and feelings), *taha tinana* (the physical side), and *taha whānau* (family) that blend to form a comprehensive and integrated model for health (Durie, 1985).

(Ministry of Health, 2001; Palliative Care Subcommittee, 2007), emergency departments (Laurensen et al., 2013), ambulance services and pharmacists. It also extends across service sectors such as Work and Income New Zealand in the social service sector. The majority of palliative care needs of the dying, in reality, are managed and met by whānau/family caregivers (Gott, Allen, Moeke-Maxwell, Gardiner, & Robinson, 2015; Gott et al., 2018; Moeke-Maxwell, Nikora, & Te Awekotuku, 2014).

Changes in the population of New Zealand (size and composition) will have major health policy, funding and planning implications (Associate Minister of Health, 2016). They will also have implications for whānau in relation to future Māori palliative care needs. For example, the proportion of Māori deaths relative to the total deaths in New Zealand is expected to remain fairly constant over the next 30 years (10.9% by 2038) (McLeod, 2016), however, the Māori population is projected to grow beyond 1 million by 2038 (Statistics New Zealand, 2017). A significant feature of this period is the increasing age at which Māori will die (McLeod, 2016). This may mean an increase in the prevalence of diseases associated with old age, such as dementia (Kerse, Lapsley, Moyes, Zawaly, & Hayman, 2017), amongst Māori warranting further consideration for the type and appropriateness of palliative care services and supports required in the future by Māori who are dying and their whānau.

## A whānau model of palliative care

Whānau/family have a crucial role in the care of people with palliative care needs; they provide the bulk of the care that is required (Gott et al., 2015; Gott et al., 2018). The whānau/family caregiver role includes looking after personal needs (bathing, cooking, toileting), administering medication, providing spiritual care, and managing visitors and visiting health professionals (Angelo & Wilson, 2014). Caregiving practices by Māori carers can incorporate a range of traditional Māori cultural customs, such as the use of *te reo Māori* (Māori language), *rongoā* (traditional healing), *mirimiri* (massage), protocols of *tapu* (restricted, sacred) and *noa* (normal, safe), *karakia* (incantation, prayer), *waiata* (song, singing), *kaumātua* (elder) guidance and support for cultural practices, *kai* (food), care of personal valuables, use of linen and the disposal of body tissue (Johnston Taylor, Simmonds,

Earp, & Tibble, 2014). Moeke-Maxwell et al. (2014) found that cultural practices can help to sustain and strengthen whānau carers, increasing their resilience in trying times to cope with the many medical, social, economic, structural and systemic issues that they face.

## Challenges whānau face

Whānau are diverse and have various capacities and resources to provide care to a dying loved one. These range from large whānau who are well connected to *te ao Māori* (the Māori world, cultural resources – land, marae, language, traditional practices), well-organised, able to share the care of a dying whānau member across the whānau and can navigate services well (Moeke-Maxwell et al., 2014), to a sole caregiver with limited or no whānau support (Johnston Taylor et al., 2014; Moeke-Maxwell et al., 2014) or, on occasion, an individual Māori person with palliative care needs who does not want whānau to provide their care (Moeke-Maxwell & Nikora, 2015, 2018).

Where Māori with a life-limiting illness reside may influence who provides their palliative care and accessibility of palliative care services. Urbanised Māori with palliative care needs may not have enough whānau support leaving them reliant on friends, neighbours or service providers (Moeke-Maxwell & Nikora, 2015). Correspondingly, for Māori living in rural areas, particularly remote rural areas, local palliative care services may be limited or non-existent (Penney, Fieldhouse, & Kerr, 2009).

Preferences of care may differ between patient and their whānau. Findings from the Kia Ngawari Study (Moeke-Maxwell et al., 2014) discusses the concept of *rangatiratanga* (autonomy, self-determination) where terminally ill participants maintained their independence by continuing normal life patterns for as long as possible, with some rejecting offers of help from whānau. For some of the participants this included managing their own health requirements (attending appointments, administering medication), and for others, like kaumātua, honouring obligations and contributing to whānau and community (Moeke-Maxwell et al., 2014). Dyall, Kerse, Hayman, and Keeling (2011), in a pilot study of Māori in advanced age in the Bay of Plenty and Lakes area, found that many Māori in advanced age

were actively involved in whānau, *iwi* (tribal), *marae* (traditional gathering place) and community.

Oetzel, Simpson, Berryman, Iti, and Reddy (2015) also found that autonomy and self-determination were of significance to kaumātua and was sometimes at odds with *whanaungatanga* (relationships, connections). The change in role for kaumātua, according to Oetzel, Simpson, Berryman, Iti, et al. (2015), from being the leader in the whānau, to someone requiring care, challenges kaumātua dignity and *mana* (spiritual connection, supernatural force in a person<sup>2</sup>), and requires a balance of relationships within the whānau. Further, Moeke-Maxwell and Nikora (2018) found that in some extreme cases kaumātua resist their whānau from being involved in their end of life journey to protect them from being overburdened. Kaumātua recognise the constraints their whānau experience (financial hardships, housing, work or other care commitments). This is supported by findings of a New Zealand longitudinal study, Te Puawaitanga o Ngā Tapuwae Kia Ora Tonu – Life and Living in Advanced Age, where there was a clear preference for older Māori “...to not be a burden to family” (Gott et al., 2017 p 3).

There are a range of financial costs associated with caring for a dying whānau member. Gott et al. (2015) carried out a cost of caregiving study in Auckland with Māori and non-Māori participants. Findings from the study suggest that these costs can be significant. Direct costs for whānau include transport and parking for appointments and hospital admissions, clothing and linen, GP visits and medication, alternative therapies, and food. Indirect costs experienced as a result of caregiving comprise of exhausting annual and sick leave entitlements or forgoing employment altogether (Gott et al., 2015). For Māori, there were specific financial costs associated with cultural customs at end of life. *Manaakitanga* (hospitality, generosity, kindness) of the ill person/turoro and *manuhiri* (visitors) for example, required not only excellent care of the ill and dying person but also of those who visited them before death. This includes obtaining (purchasing) *kai rangatira* (special food) for the ill person. Kaumātua often desire specific foods of their youth, for example, *kaura*

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<sup>2</sup> As defined by (Oetzel, Simpson, Berryman, Iti, et al., 2015).

(crayfish). Telephone accounts might increase as the ill person increases contact with whānau who live at a distance to them. Another cost is incurred (travel, food) when returning to ancestral homes to visit whānau, sacred landscapes and *urupa* (cemetery) prior to death (Gott et al., 2015; Moeke-Maxwell et al., 2014).

## A Western model of palliative care

Palliative care is a health care approach where the central concern is the quality of life of patients and their families facing problems associated with a life-threatening illness, by preventing and relieving suffering (World Health Organisation, 2002).

In New Zealand, palliative care is delivered through specialist and generalist services. Specialist palliative care has been defined as “...palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals” (Palliative Care Subcommittee, 2007 p. 4). According to the New Zealand Palliative Care Strategy (Ministry of Health, 2001), specialist palliative care can be provided from a hospital or hospice and offer essential palliative care services (assessment and co-ordination, clinical care, support care). Generalist palliative care is provided by any healthcare professional not part of a specialist palliative care team (general practice teams, district nurses, allied health teams, residential care staff, Māori health providers, general ward staff in hospitals) (Palliative Care Subcommittee, 2007).

The Ministry of Health (2001) outline five guiding principles that underpin palliative care in New Zealand. These are:

- Focus is on the person who is dying and their whānau/family.
- Dying people are informed of their palliative care entitlements and have access to quality services that are appropriate to their needs.
- Uniqueness, autonomy and culture of each person is respected, and all care is based on their specific needs and wishes.

- A multidisciplinary approach with continuity of care (before, during and after diagnosis) to achieve total care for the person

## What is working well

Some whānau who provide end-of-life care are setting up well to do this critical work. When whānau have a good understanding of the health system, good access to statutory resources (carer benefits etc.) and the information they want or need to know (regarding illness, prognosis and treatment), and/or where services are flexible and able to adjust to the diverse needs of whānau, the palliative care trajectory generally works well for whānau.

Research findings indicate that Māori accessing palliative care services, such as hospice, have positive experiences across many aspects of care received. Johnston Taylor et al. (2014) conducted a kaupapa Māori qualitative study examining Māori perspectives of hospice care in the Wellington region. Positive experiences included:

- respite care easing the strain on whānau carers,
- access to equipment and information pertaining to patient care,
- bereavement support,
- spiritual care, and
- compassionate staff.

Slater et al. (2015), in a study of Māori cancer patients' and their families, identified findings consistent with Johnston Taylor et al. (2014), and further add:

- continuity of care,
- after-hours support,
- hospice inpatient units being responsive to whānau needs (beds, kitchen facilities),
- whānau feeling included and supported,
- good communication, and
- assistance to apply for benefits and arrange funerals.



## Where are the gaps?

Evidence reveals gaps and inconsistencies in the provision of appropriate palliative care services to Māori. Gaps are exacerbated for whānau who have limited resources and poor access to information.

### *Information, entitlement and access*

A cross-cultural qualitative study found that challenges to hospice service utilisation “...were underpinned by the cultural differences between the communities served and the suppliers of health services” (Frey et al., 2013 p. 522). Research participants attributed poor uptake of services to a lack of awareness of hospice services, barriers to accessing good information, and fears of discrimination based on their own or others’ experiences within the health system.

A principle of palliative care in New Zealand is that all dying people should be informed of their palliative care entitlements (Ministry of Health, 2001). Research findings suggest, however, that there is a low level of awareness or misconceptions of palliative care services amongst Māori (Frey et al., 2013; Johnston Taylor et al., 2014; Penney et al., 2009) and a lack of appropriate information about palliative care and the range of palliative care services available (Kara, 2008; Penney et al., 2009). Frey et al. (2013) suggest that misunderstanding and misinformation exist where good information is lacking.

Entry into palliative care pathway can be hindered by late referrals. Māori health providers participating in a study in Te Tai Tokerau expressed concerns over late referrals of Māori into specialist palliative care services (Penney et al., 2009). Late diagnosis can also contribute to late referrals into palliative care. Participants in a small kaupapa Māori study in Hawkes Bay reported varying experiences of being diagnosed with a terminal illness (Koti, 2013). In one case there was a lengthy delay in diagnosis, despite having attended GP appointments for the same complaint over a number of years. However it occurs, late entry into specialist palliative care services may mean that Māori do not have the opportunity to benefit from the full range of palliative care services available.

## *Information and communication*

In relation to the principle of 'quality of life' (Ministry of Health, 2001) some research participants have identified a dearth of information regarding what to expect during the palliative period. They view that having this information would better prepare the patient and their whānau, and prevent unnecessary feelings of fear (Penney et al., 2009).

Research participants also identified issues relating to the use of medical jargon, a lack of respectful communication (Penney et al., 2009), and the way in which some physicians communicated diagnoses of a terminal illness (Koti, 2013). Findings support more effective communication and information is required from healthcare professionals (Moeke-Maxwell et al., 2014; Oetzel, Simpson, Berryman, & Reddy, 2015; Penney et al., 2009).

## *Cultural respect and understanding*

According to Harris et al. (2006), the experience of racial discrimination in New Zealand is likely to be a major health risk and a contributor to ethnic health inequalities. The literature reviewed for this report indicate that some terminally ill Māori and/or their whānau have experienced racism while receiving care (Moeke-Maxwell et al., 2014; Penney et al., 2009). For example, in one case a terminally ill Māori patient in an urban hospital was stereotyped as a drug user and had pain medication withheld (Moeke-Maxwell et al., 2014). Māori experiences of the health system can influence uptake of services and completion. Further, Frey et al. (2013) found that fears of discrimination can be derived from others' experiences within the health system.

## **Indigenous perspectives**

The indigenous experience at end of life is not dissimilar to that of Māori. Indigenous peoples' constructs of death and dying differ from the Western medical model. Hampton et al. (2010) in a study of First Nations people in Canada, and Dembinsky (2014), in a study of Yamatji people in Australia, found that death was considered a normal and necessary part of life. Death is typically viewed as part of a continuum (Dembinsky, 2014), or a wheel (Hampton et al., 2010), where the spirit transitions to another phase (Duggleby et al., 2015).

In Hampton et al. (2010) a participant referred to end-of-life care as a time where “...care and comfort of the heart and spirit take precedence...” (p 11). A critical role that Māori whānau have in end-of-life care for kaumātua is the preparation of their spirit to transition to the afterlife (Moeke-Maxwell & Nikora, 2018 (publication pending)).

## Family and caregiving

Family caring for their own can be an important traditional value, though one not necessarily shared by all (McGrath, 2008). According to McGrath (2008), Aboriginal people in Australia provide care for their dying, such as personal care (toileting, hygiene, washing), managing medicines and dressing, housework, cooking and taking their loved one to appointments. In addition, care also encompasses constant spiritual and emotional support, preparation and provision of bush food, and sharing music and song (McGrath, 2008).

The availability of appropriate support for Indigenous palliative care patients and their family is a key theme surfacing in research (McGrath & Holewa, 2006; O'Brien, 2012). Carers come under significant stress (physical, emotional, financial) which can be exacerbated by a lack of local services (McGrath, Holewa, & Kail-Buckley, 2007; McGrath et al., 2006), poverty (McGrath & Holewa, 2006), geographic challenges (remoteness, travel) (McGrath, Holewa, & McGrath, 2007), and different cultural perspectives and practices to those of Western health care providers (McGrath, 2008). According to the findings of O'Brien (2012), appropriate support includes relief for family carers (respite, overnight support), counselling, regular and respectful communication, respect for and flexibility regarding cultural practices associated with the end of life, and financial assistance.

## Cultural preferences

Cultural preferences, such as place of death, can have important implications for indigenous people. Dembinsky (2014) found that it was a cultural imperative for Yamatji people to die within their own ‘country’ as it enabled them to complete the continuum of life and death. Being within their own ‘country’ provided a connection to ancestors, peace and comfort, and added to the quality of life to the dying person. Hospital-based palliative care services located outside Yamatji ‘country’ were deemed inappropriate (Dembinsky, 2014). In

another study, indigenous elders in Canada indicated a preference for home but acknowledged that sometimes, due to the level of care required, this may not always be appropriate (O'Brien, 2012). Further, being at home may be prohibited by a lack of local services, such as respite care (McGrath et al., 2006). For other indigenous peoples', death at home is avoided due to traditional practices. An example is the customary burning of a trailer or caravan amongst Irish Travellers (McQuillan & Van Doorslaer, 2007).

### *Barriers to indigenous access of palliative care*

Different understandings of end-of-life care between Indigenous people and people entrenched in the Western biomedical model can result in barriers of indigenous access to appropriate care. Such differences can lead to communication issues, discrimination, and policies that restrict traditional practices (Hampton et al., 2010).

Being able to carry out cultural traditions and practices surrounding illness, death and dying are an important part of care for indigenous people (Dembinsky, 2014; Hampton et al., 2010; O'Brien, 2012), but dying in hospital is not always congruent with indigenous cultural practices (Dembinsky, 2014). A small Canadian study of Aboriginal elders found that institutional policies, informed by Western notions of what is good for the patient, can obstruct the practice of traditions (Hampton et al., 2010). Gathering of family and community around a dying one is common practice among indigenous people identified in research in Canada and Australia (Hampton et al., 2010; Kelly et al., 2009; McGrath & Holewa, 2006). Visiting hours and limiting the number of visitors can prevent families and communities from gathering, thereby preventing them from carrying out traditional practices for their loved one, such as those that care for the spirit (Hampton et al., 2010).

Indigenous perceptions of palliative care can also act as a barrier to access. Dembinsky (2014), in a study exploring indigenous perceptions and use of palliative care services in Australia, found that the Yamatji people strongly associated palliative care services to care for those who are on the verge of death. Correspondingly there is low uptake of palliative care services.

Geography and location of services can also be barriers to access for indigenous people, particularly when cultural imperatives are important to a dying person and their family. Other themes in the literature regarding issues of access concerning geography and location are remote populations of indigenous people and limited service availability (Dembinsky, 2014; McGrath et al., 2006).

## Cultural respect and cultural competence

Using Western medicine can invoke feelings of fear and powerlessness (McGrath & Holewa, 2006), particularly the during end-of-life journey when a patient is very vulnerable. Research has found that providers of palliative care need to be aware and respectful of cultural traditions of indigenous peoples, especially those of a religious or spiritual nature (McGrath & Holewa, 2006; O'Brien, 2012). Hampton et al. (2010) findings express a need for healthcare professionals to be appropriately educated to work effectively with indigenous people.

Communication during end-of-life is extremely important. Research findings indicate that it must be clear, direct, respectful communication (Kelly et al., 2009). Further, research participants in Hampton et al. (2010) raised notions of working together (traditional healers and Western physicians) as a way of improving care for indigenous people.

## Suggested improvements

Areas for improvement of palliative care services have been identified in research and are outlined below.

### Workforce development

Research findings support appropriate workforce development to better meet the needs of Māori with palliative care needs and their whānau. Findings include increasing the number of Māori working in palliative care (Frey et al., 2013; Koti, 2013; Penney et al., 2009) and palliative care training for all services and providers that contribute to palliative care (Penney et al., 2009), including appropriate training for Māori health providers (Kara, 2008).

## Communication and information

The development of culturally appropriate resources and information for whānau will help to improve the understanding and awareness of palliative care, and positively influence the uptake of palliative care services. Further, developing cultural resources that increase the awareness of traditional practices may contribute to improved resilience amongst whānau caring for loved ones, and overall improve experiences at end of life for the ill person and their whānau.

A Health Research Council funded study currently underway, Pae Herenga, aims to:

- Investigate end-of-life Māori care customs that Māori whānau draw on to strengthen their end-of-life caregiving activities and support palliative care provision.
- Identify barriers and facilitators Māori experience to using these care customs within different care settings (home, hospice, hospital and aged residential care).
- Develop an educational online resource for Māori whānau, their communities and the palliative care sector.

## Cultural safety and cultural competency

According to Durie (2001), cultural safety and cultural competency “...are about the relationship between the helper and the person being helped, but cultural safety centres on the experiences of the patient, or client, while cultural competence focuses on the capacity of the health worker to improve health status by integrating culture into the clinical context...” (p 2). Reid and Robson (2007) state that it is difficult to improve Māori health status without first understanding the colonial history of Māori. They assert that colonisation must be recognised as a deliberate process and that it is one that continues to impact upon Māori. It is within the colonial context of New Zealand that the concept of cultural safety first arose (Papps & Ramsden, 1996) to address quality issues in health care relating to access and communication (Ramsden, 1995 in Papps & Ramsden, 1996).

Research participants have identified experiences of palliative care services that have not been culturally safe. In one case a Māori hospice patient asked a Māori health provider to intervene and resolve a cultural safety issue with hospice (Slater et al., 2015).

Durie (2001) describes cultural competence as an acquisition of skills that help to gain a better understanding of members of other cultures and is “...another dimension to the doctor patient relationship that can provide doctors with additional information necessary for better clinical results” (p 4). Competency training for all staff and services involved in the delivery of palliative care to Māori was supported by research findings (Penney et al., 2009).

## Conclusion

It is imperative that Māori with a life-limiting illness and their whānau are fully informed. Communication must be clear. All information regarding diagnosis, palliative care service entitlement and availability, including services outside of the health sector, must be provided.

The literature points to specific palliative care cultural competency training needs. Interactions must be respectful and free from preconceived notions of culture, spirituality and what is best for the patient. Patient and whānau/family needs and wishes must be understood and respected.

A systemic approach to caring for Māori who are dying and their whānau is required. It must take into account that Māori are diverse. What Māori with a life-limiting illness want or need from their whānau or palliative care services may differ from person to person and whānau to whānau. Providers of palliative care need to be flexible in their approach to working with terminally ill Māori and their whānau.

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